
CHARTER

OF THE

KANSAS ADVISORY COUNCIL ON NEWBORN SCREENING

Effective Date: May 15, 2008
Last Revision Date: November 15, 2025

ARTICLE I. AUTHORITY AND MISSION

The Kansas Advisory Council on Newborn Screening (KACNS, sometimes referred to as “KACNS” or the “Council”) was established under amendments to KSA 65-180 in 2007 by the Kansas Legislature to advise the Kansas Department of Health and Environment (KDHE) on the implementation of a comprehensive, quality system for the screening of all Kansas newborns and for follow up, counseling and health care services for those having or at risk for heritable disorders.

ARTICLE II. PURPOSE

The purpose of this Charter is to establish operational guidelines for the conduct of business of the Kansas Advisory Council on Newborn Screening.

ARTICLE III. MEMBERSHIP

The membership of the KACNS shall not be less than 15 nor more than 25 voting members appointed by the secretary of KDHE. Members shall be representative of stakeholders with interest in and concern for screening of newborns for congenital and inherited diseases/disorders and conditions and inborn errors of metabolism. Members shall be appointed for three-year terms and may be reappointed for additional term(s). The Secretary of KDHE shall approve the appointment of a person to fill any unexpired vacancy.

Ideal membership may consist of representation from the following categories: pediatric specialist relevant to each disorder screened (e.g., pediatric hematologist for hemoglobinopathies; pediatric metabolic specialist for metabolic diseases pediatric endocrinologist); pediatrician practicing in a Kansas community; family physician practicing in a Kansas community; neonatologist; pathologist; laboratory Ph.D. level or above chemist; hospital representative; registered/licensed dietitian practicing at a Kansas metabolic clinic; geneticist; genetic counselor; nurse practitioner practicing at a Kansas metabolic clinic; parent or consumer representative for each disorder, or class of disorders screened; medical ethicist; and such others as the Council determines necessary. Some members may fulfill representation of more than one role.

The KACNS members shall:

1. Attend biannual Council meetings and/or participate in meetings conducted by conference call;
2. Give prior notice to the assigned newborn screening staff member if unable to attend or participate in a biannual Council meeting; two consecutive missed meetings may result in dismissal from the Council;
3. Participate in committee meetings which may be conducted in person at the biannual meeting, by teleconference, interactive email, or other electronic means for holding meetings;
4. Review agenda items and the supporting documentation before meetings;
5. Provide input on ideas and participate in discussions;
6. Review and comment on research, reports and other background information;

7. Recommend strategies for program improvement;
8. Vote on issues requiring a vote;
9. Provide to the KDHE Secretary nominations of candidates to fill vacant member positions;
10. Tender their resignation in writing to the newborn screening leadership;
11. Abide by the requirements of the Conflict of Interest Procedures, Disclosures and Responsibilities for Members on the Kansas Advisory Council on Newborn Screening, which will be signed by the member;

Members shall not participate in legislative activity in the name of the Council or KDHE. Council members may represent themselves or other entities in the legislative process.

ARTICLE IV. CHAIR/VICE-CHAIR MEETINGS

The Council shall elect a Chairperson and Vice-Chairperson from KACNS voting members by majority approval who shall preside for a term of two years. The Chairperson shall have in addition to the responsibilities of regular members the following additional responsibilities:

1. Preside over semiannual meetings and emergency meetings;
2. Approve meeting agendas;
3. Decide points of order;
4. Call for votes on issues;
5. Consult with Vice-Chair and program staff in developing reports and recommendations;

The Vice-Chairperson shall have the same responsibilities as regular members and will perform all the duties of the Chairperson when that person is absent or incapacitated. The Vice-Chairperson may serve as Chairperson when that position has been vacated until the membership is able to select a new Chairperson.

ARTICLE V. MEETINGS

The KACNS shall meet semiannually and at other times as needed in person or through teleconference, videoconference or other electronic means for holding meetings. The Chairperson may call for emergency/interim meetings at his/her discretion. The semiannual meetings are open to the public.

The KACNS must have a simple majority of the voting membership to constitute a quorum at any meeting including teleconferences or other electronic means for holding meetings. The Council may meet without a quorum but may not conduct votes on any official business.

Issues requiring a vote must follow *Roberts' Rules of Order*. A simple majority of the quorum voting in favor of the motion is needed for the motion to pass. Issues requiring a vote are those that would require significant change by the program, such as addition of a new disease to the required screening panel, regulation or statutory revision, or other items as determined by members of the council. The official determination by votes will be transmitted via formal written notification to be transmitted to KDHE Executive Leadership.

ARTICLE VI. COMMITTEES

KACNS may establish subcommittees as necessary to assist in the carrying out the duties of the Council. Subcommittees may be utilized by the KACNS as deemed appropriate by the Council for review of special topics on an ad-hoc basis. Subcommittee membership may include members and non-members of the Council in order to obtain appropriate professional and technical expertise relevant to the topic. The subcommittees must report discussions and/or findings back to the full council. The following standing subcommittee shall be established to carry out the duties of the Council.

Clinical and New Conditions. This committee will assist in the development of methodologies and protocols guiding screening, short-term and long-term follow-up diagnosis and general management of newborns with heritable disorders for conditions to be added to the newborn screening panel. It may recommend clinical conditions to be added or removed from the screening panel. The Clinical and New Conditions subcommittee may also request a review of condition specific activities, methodologies, information, etc., as determined necessary by the full Council or subcommittee.

ARTICLE VII. MISCELLANEOUS

Section 1. Quality Assurance: The Newborn Screening Program will issue reports at least once per year that reflect measures of quality on all aspects of the screening system, including but not limited to: specimen collection, handling and transport, laboratory testing, laboratory reporting, initial notification, follow-up and retrieval, confirmatory testing, and for infants with a confirmed diagnosis for each of the diseases screened: diagnosis, management and treatment outcomes. The KACNS shall make recommendations for strategies the program may employ to improve on any quality assurance measure deemed by the Council to need improvement.

Section 2. Composition of Screening Panel(s): Any member of the Council or Program Staff may request review of a condition or conditions for addition to or deletion from the newborn screening panel. The actual review of a condition(s) must be approved by a simple majority of the Council. The KDHE Newborn Screening Program must make all review materials available to the Council membership at least 2 weeks prior to the next meeting.

Section 3. Technology Review: The Council shall be provided an opportunity to thoroughly review technical aspects and clinical utility of analytical test methods proposed for use by the Kansas Health & Environment Laboratory (KHEL) Health Chemistry Section, Newborn Screening Unit, or subcontractors. Following such review, the Council shall document recommendations of approval, disapproval or modification of any aspect of the methodology.

ARTICLE VIII. PROGRAM STAFF

The KACNS shall be assisted in its work by the Newborn Screening staff of the KDHE. The Blood Spot Screening Program, including but not limited to, the Blood Spot Follow-up and KHEL Manager, and the Blood Spot Follow-up Support Team shall provide support to the Council in the following ways:

1. Locating, organizing and preparing pertinent background information;
2. Interpreting programmatic policies, regulations and statutes;
3. Drafting reports and meeting minutes;
4. Making meeting arrangements;
5. Collaborating with the Council Chair and Vice-Chair in establishing meeting agendas and approval of meeting minutes;
6. Writing reports for the review, revision and approval of the Chair, Vice-Chair and membership on recommendations to KDHE.

ARTICLE IX. AMENDMENTS

This charter may be amended by the Council at any meeting, by a two-thirds vote of those voting, a quorum being present, provided at least ten (10) days notice of the proposed amendment has been given to the membership in writing.